

Participant Experience Survey: Overview

The Participant Experience Survey (PES) is a series of survey tools that States may consider using as part of their quality management program, to monitor selected dimensions of quality in their waiver programs. The purpose of the PES is to provide State officials with information about program participants' experience with the services and supports they receive under the 1915c waiver program (the Medicaid Home and Community Based waivers). The PES instruments were developed by The MEDSTAT Group, Inc. (Medstat) under contract to the Centers for Medicare and Medicaid Services (CMS), an agency of the U.S. Department of Health and Human Services (DHHS).

The PES tools are designed to be administered in-person to a sample of waiver participants. The resulting data can be used to identify areas where program participants are experiencing unmet needs or other quality problems. These identified problems can then be addressed systematically across the waiver as a whole, or on an individual basis. Data from the PES can also be combined with data from other sources.

Target Populations

There are currently three versions of the PES:

The **PES Elderly/Disabled** version (PES E/D) is designed for elderly and non-elderly adults with physical disabilities, and can be used to calculate 33 indicators related to program quality. The **PES E/D Users' Guide** provides detailed instruction on administering the survey and calculating the indicators.

The **PES, MRDD Version (PES MRDD)** is intended for use with adults with Mental Retardation and/or Developmental Disabilities. This tool yields 51 indicators; information on calculating the indicators and using the tool can be found in the **PES MRDD Users' Guide**.

Both the PES E/D and PES MRDD capture information on participant experience in the following four domains. Indicators can be calculated within each domain for quality monitoring and intervention.

Access to Care: Are program participants' needs for personal assistance, adaptive equipment, and case manager access being met?

Choice and Control: Do program participants have input into the type of services they receive and who provides those services?

Respect/Dignity: Are program participants treated with respect by providers? Are they experiencing abuse or theft?

Community Integration/Inclusion: Do program participants participate in activities and events of their choice outside their homes, when they want to?

The PES E/D and PES MRDD were developed under the guidance of a Work Group comprising state Medicaid waiver staff, CMS Regional and Central Office staff, representatives of disability groups, and experts in survey methodology and disability research. Both surveys were tested extensively prior to their release, including both cognitive testing and field testing. A detailed summary of the development and testing process can be found in the **Final Report**.

A third survey, the **PES, Brain Injury Version (PES, BI)** was developed for adults with acquired brain injuries, which includes both traumatic brain injuries, as well as brain injuries from other sources, such as strokes and tumors. It can be used to calculate up to 58 indicators, depending on what portions of the survey are used. Guidance on calculating the indicators and on using the tool with this population is included in the **PES BI Users' Guide**.

The PES BI is organized into the four domains listed below. Two additional sets of questions can be added if relevant to the scope and structure of a State's waiver program.

Program Supports: Are program participants satisfied with their current living situation? Do they have access to case manager and other services?

Choice and Control: Do program participants have input into the type of services they receive and who provides those services?

Respect and Dignity: Are program participants treated with respect by providers? Are they experiencing abuse or theft?

Community Activities: Do program participants have an opportunity to engage in community activities outside their homes, including work, a day program, or volunteer activities?

The two additional modules include more detailed community integration items and questions about unmet need for assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs).

Technical assistance with using any of the three PES versions, including assistance with sampling, interviewer training, and data analysis, is available through the [National Quality Contractor](#). Contact Sara Galantowicz at sara.galantowicz@thomson.com for more information on obtaining technical assistance.

PES Software

CMS has released free software that automates the PES E/D and PES MRDD tools. This software allows interviewers to enter program participants' responses directly into a laptop or desktop computer. Responses from multiple computers are automatically collated into a master database, which can be analyzed using pull down menus. The two PES software packages include the following features:

Ease of Installation: Each software CD includes simple instructions for loading the software and desktop icon. The PES software requires Windows 2000 or Windows XP to function. Through the install program, States receive all the necessary components to run the software, and no additional software licenses are required.

Ease of Use: Survey responses are stored in an Access database that resides on the computer. Completed interviews can be easily downloaded to a central database. In addition, states can add their own questions to the end of the survey, and make some language substitutions in existing questions. However, States may not change or delete the original PES questions.

Ease of Analysis: The PES software has a built-in capability to analyze survey responses, calculate indicators, and generate reports for quality improvement activities. The software automatically calculates the indicators for each survey version, which can be stratified by a number of user-defined demographic variables. In addition, the survey data can be exported into selected other software packages for additional statistical analysis.

Protection of Confidential Health Information: Both the data collection software and the resulting database are password-protected, to safeguard personal health information. In addition, the summary reports generated by the software do not include any information that could be used to identify individual participants.

To obtain a copy of the PES E/D or PES MRDD software, and/or a UserID and password that are required to operate the software, please e-mail Sara Galantowicz at sara.galantowicz@thomson.com, our contractor for the PES software. CMS is providing technical assistance to states interested in using the PES software through the National Quality Contractor, Medstat. For more information, contact Sara Galantowicz at the address above.